

Essential healthcare for people with learning disabilities: barriers and opportunities

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The past 30 years have seen far-reaching and radical changes in our attitude towards people with learning disabilities and in the values that inform and guide the development of services for them and their carers. A growing emphasis on the provision of services in the community has led to the closure of long-stay hospitals and greater inclusion in the wider society. Successive governments have set out to create the conditions under which community care may be successfully developed. The delivery of health services as an essential part of community care has been placed firmly within this framework, as shown in the extension of the *Health of the Nation* strategy to people with learning disabilities¹. Elsewhere, a comprehensive consensus statement on the development of a responsive framework for the healthcare of people with learning disabilities has been provided².

As the Department of Health acknowledges³, however, 'Significant problems were reported in the re-shaping and development of appropriate and accessible primary, specialist and continuing health care services, especially for people with complex or additional physical or mental health care needs'. This conclusion is confirmed in many statements from people with learning disabilities and their carers⁴. This paper is concerned with the reasons why access to and quality of primary healthcare services have posed such problems, with a focus on the role of the general practitioner (GP).

THE ROLE OF PRIMARY HEALTH SERVICES

The right of people with learning disabilities to use community and hospital health services, and the central role of GPs in providing for their healthcare, are rarely in dispute². Certainly the GP is the health professional most frequently contacted by them and their carers⁵. Most consultations take place in the surgery⁶, and GP opinion is divided on whether people with learning disabilities require more home visits than does the general population⁷. Consultation rates are lower than those of the general population⁴, though higher rates of consultation with specialists have been reported.

Typically, GPs do see themselves as the most appropriate people to provide healthcare for people with learning disabilities^{7–10}. However, a minority of GPs view them as an unwelcome burden⁷, requiring additional funding if such objections are to be overcome.

WHAT GOES WRONG?

Direct assessments of health have also indicated unmet health needs unknown to GPs¹¹, while healthcare decision-making can be disturbingly poor¹². Barriers to delivery of a good service include communication difficulties and the effect of challenging behaviour during consultations, coupled with lack of adequate consultation time^{13,14}. Self-referral is rare, again in part because of communication difficulties but also because carers do not identify healthcare needs. Agencies that commission social care should ensure that the physical care of service users gets high priority both in the training of care staff and in the relevant review processes. Another frequently cited barrier is the GP's lack of knowledge of health needs and diagnostic procedures relating to people with learning disabilities. Many practices lack information on who has learning disabilities and their health status. There exist models of good practice to improve the quality of healthcare decisions¹².

IMPROVING PRIMARY CARE SERVICES

Members of the primary healthcare team need to be aware of any communication difficulties the person may have, and effective communication may require the help of a family carer, a member of professional staff or a citizen advocate. GPs can obtain information on best practice for interviewing people with learning disabilities¹⁵. In addition, some learning-disabled individuals may need to be prepared for the consultation by progressive familiarization with the setting and the removal of cues associated with previous negative experiences.

Issues of informed consent remain problematical while legislation is pending. The aim, however, must be to avoid inappropriate discussion and/or coercion before or after an examination. Not infrequently carers are asked to consent to treatment on behalf of a person with learning disabilities; this cannot be done within the law.

Might systematic surveys of health identify unrecognized illness and ensure that the person is participating in appropriate health promotion initiatives^{16,17}? Screening of this kind has revealed substantial numbers of unidentified conditions, and in one study subsequent gains in physical, though not mental, health were reported¹⁶. Only a minority of GPs seem willing to undertake screening at present^{7,8}, whether they would undertake the task themselves or delegate it to other members of the practice. For such checks to be accepted by GPs, there is a need for good quality evidence of their clinical effectiveness—and possibly appropriate remuneration. In future we might expect general health checks and screening programmes to be complemented by more specific medical surveillance for given conditions such as Down syndrome¹⁸.

Screening and health checks for those with learning disability should not be seen as a substitute for generic screening programmes, especially in women, whose uptake of breast and cervical cancer screening is inadequate. Most GPs support equity of access to these services, but there is a lack of clarity about the circumstances in which they should be offered or pursued. A publication from the NHS cancer screening programmes is an important step forward¹⁹.

Matters would be further improved if people with learning disabilities had access to better healthcare information. This would help them to identify and report their own symptoms. Educational initiatives are increasing and there is a growing body of published material on healthcare issues designed to be accessible to people with learning disabilities. At a local level such material is most likely to be provided by specialist services working in conjunction with health education agencies. Not all GPs regard health promotion as part of their responsibilities⁷.

There is also an important role for specialist provision⁷, but contact between GPs and specialist learning disability teams is at a low level. Contact can be strengthened by link worker schemes operating between teams and primary care⁷.

MEDICAL EDUCATION AND KNOWLEDGE OF LEARNING DISABILITY

Undergraduate education

Although 'handicap, disability and rehabilitation' has been identified as one of eight important themes in the core curriculum²⁰ the subject of learning disability receives only cursory treatment in initial medical training, postgraduate studies or continuing medical education. GPs themselves indicate that they gained little from undergraduate training on learning disability and are conscious of their lack of expertise in this area⁹. Nevertheless, a majority of GPs in a recent survey⁷ thought further training unnecessary in view of the small number of people with learning disabilities they saw. In fact, the average single practice will have 150

people with such disabilities, of whom 30 have severe or profound learning disabilities. With respect to undergraduate medical education, a 1987 survey of all medical schools²¹ indicated an average time of 11 hours throughout the course, with two deans saying that learning disability was not part of the core curriculum. Those who taught on learning disability saw their principal goal as to provide medical students with the knowledge, understanding and experience that would enable them to provide appropriate treatment whatever their eventual specialty. We lack information on how far matters have changed in the subsequent 14 years—or indeed on whether courses with specific aims related to learning disability produce more effective doctors. At St George's Hospital Medical School an innovative approach includes considerable input from people with learning disabilities²². Family carers ought to be more involved in medical education, with their unique and intimate insights. What sort of support and training do they require if they are to contribute in this way?

An excellent framework has been published²³, including a list of subjects which can be illustrated with examples from disability and rehabilitation grouped under the topics of ethics and rights, basic science, clinical science, social science and management of services. The British Society for Rehabilitation Medicine in 1996 published suggestions for the content of a core curriculum on disability in general²⁴.

Continuing medical education

Continuing medical education (CME) for GPs has fared equally poorly. A recent paper reviewed 36 studies assessing GPs' educational needs, none of which were related to learning disability²⁵. Similarly, the introduction of the postgraduate education allowance, for GPs meeting specified targets with respect to CME, had little impact on initiatives concerned with learning disability, while *Health of the Nation* priorities, though relevant to people with learning disabilities, have little bearing on education about learning disability.

Clearly the Chief Medical Officer's proposal to replace the postgraduate education allowance by practice professional development plans and personal learning portfolios will radically alter the potential routes through which doctors will gain information on learning disability. Though such approaches may offer more effective ways of ensuring continuing education, their link to target areas may still further reduce CME related to learning disability.

The present aim, therefore, should be to ensure that GPs have a wide range of information sources on learning disabilities. These include specialist internet databases, provision of information by specialist voluntary organizations, and national availability of speaker panels. Directories such as the *Contact a Family Directory* and *In Touch* provide

links to a wealth of specialist groups. Articles in GP magazines, in retainable format with an index, would provide a further accessible resource.

There is a real need, however, to go beyond the provision of information. Consideration should be given to the development of a distance-based learning package, with postgraduate accreditation for GPs. There is also scope to develop a learning disability training pack which could be used for medical undergraduate and postgraduate training, and also for multidisciplinary team training in primary care. Such a pack could include techniques of role play, with an emphasis on communication skills^{26,27}.

THE WIDER CONTEXT FOR CHANGE

Strategies to increase the emphasis on learning disability in CME need to be placed in a wider NHS framework applicable to education and training. Ten core principals have been proposed (originally drafted by the Directorate of Education and Training, North Thames Regional Office, 1996). These assert that education and training should fulfil a wide range of functions related to the service and its interface with research and development, as well as encouraging partnerships and cross-boundary working between academic, professional and statutory bodies, and innovative practice in the NHS. Such principles will clearly have to be implemented at several levels if they are to improve effective education and training in the primary care sector, and key areas have been identified²⁸.

The question of inadequate health services for people with learning disabilities, however, goes beyond these NHS-related issues. Of central concern are workforce planning and the integration of professional support for these individuals and their carers. Social services and health services operate with very different types of skill mix, management systems and value bases²⁹. Joint community care planning has not necessarily brought planning and delivery of services into a coherent framework, and joint management of learning disability services is now being undertaken in certain regions.

A further element of the partnership also needs to be developed by both NHS and social service staff, i.e. that with users of the services and their family and professional carers. Carers in particular are a key factor in linking primary care to the needs of the individual. GPs have drawn attention to the importance of carers in determining demand for a service⁷.

CONCLUSION

The publications reviewed in this paper suggest the need for a coherent strategy at local and national levels that embraces: (i) health education and information for people with learning disabilities and their carers; (ii) improved

health surveillance and monitoring; (iii) higher quality education and innovative training opportunities at all stages of medical training and practice; and (iv) a clear vision as to how the wider policy and strategic aims of the NHS will allow people with learning disabilities to benefit more from mainstream healthcare services.

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